## DDDS GAC Medicaid Residential Work Group May 7, 2015 1:30 p.m. – 3:30 p.m.

**Work Group Members Present**: Melinda South, Victor Schaffner, Laura Waterland, Kathie Cherry, Tim Brooks, Jamie Doane, Kimberly Reinagel-Nietubicz, Kyle Hodges, Terry Olson, Lisa Green, Frann Anderson, Eddi Ashby, and Libby Cusack

**Guest Present**: Non-committee members in attendance included: Daniese McMullin-Powell (for Bill Monaghan), Lisa Elias, Micki Edelsohn, and Carol Kenton.

**Female Speaker:** Okay. Let's just go around the table for introductions. Libby Cusack.

Female Speaker: Kathy Cherry.

Female Speaker: Lisa Green.

Female Speaker: (?) Anderson, DDDS.

Female Speaker: Eddie Ashby, DDDS.

Male Speaker: Victor Shafner.

**Male Speaker:** Tim Brooks.

Male Speaker: Terry Olson.

**Female Speaker:** I am just a, #(Inaudible 00:22) Phil Moynihan asked me to take notes for him.

Female Speaker: Jamie Hill.

Female Speaker: Laura Waterman.

Male Speaker: Kyle Hodges, STPD.

Female Speaker: Lisa...

Female Speaker: Oh, Lisa (?).

Female Speaker: Carol Kenton.

Female Speaker: Mickey (?).

**Female Speaker:** And Kimberly, are you on the phone? I don't think I heard...

**Female Speaker:** I am here Libby. Thank you for asking. Kimberly #(Inaudible 00:44). I just wanted to throw out because it's hard for me to interject sometimes, I do have a message from the other transition worker that they wanted me to convey to you guys as well at some point, so, I didn't get a chance to email you with that request.

**Female Speaker:** Okay. Just one second and we will get to that. Does anyone know about Melinda or Gary? If they are planning to attend?

Male Speaker: I'm not sure.

(Everyone talking at once)

**Female Speaker:** Dr. Terry Macy will be stopping in to introduce himself. He is our new director of community services, so I thought it would be a good opportunity for him to introduce himself, so if you need him for a resource later on, you know who he is and he can make himself available.

**Female Speaker:** And for those who were not here last week, Eddie is going to be filling in for Fran, while Fran is out for the next couple weeks, from DDDS.

**Female Speaker:** What did the lady say on, I couldn't understand what she was saying?

**Female Speaker:** Kimberly, did you want to go ahead and share, you said you had something the other group wanted to share with us?

**Kimberly:** Yeah, they just want to, in considering the questions for the residential group, they felt it was important that you guys consider something around the ability for an individual to have access to vote. There was some questions, I know you guys were using Hawaii, there were some in their assessment, and they felt it was essential that the message be conveyed to you guys and they would like feedback from you guys as to whether you will add something into your assessment around this topic. Bill Moynihan was there yesterday. I didn't hear if he's in the room or not. He may have something to add on this as well.

**Female Speaker:** He's not able to join us today.

Female Speaker: Okay.

**Female Speaker:** Okay. So, keep that in mind when we get to the questions and we will make sure we that we discuss voting as one of the assessment questions. Just quickly going through the meeting ground rules. They are being recorded, so announce your name when you speak and speak up, the recorder is over here, so if you are out on the edges, please speak up. One person talks at a time and respects when somebody else is speaking. Limit phone calls during meetings. We are going to start and end the meetings on time. Stay on agenda. And do the homework prior to the meetings. And guests may participate in the meetings, but only committee members may

vote.

Does anybody have any changes or anything they would like to discuss from the meeting transcript from last week? (Silence) I will take that as a no.

Next on the agenda is to review the action items that are open from last week and previous meetings. If you take a look, this is Libby, if you take a look at the action item list that I sent out after last week's meeting, the first open action item here is to review the items regarding lease agreements and evictions. And I think Bill, Terry provided some questions to think about on that, and I think we will get to that discussion when we finish the other questions on the list, on the assessment list.

The next one is Fran, the shared living person, from shared living to join our group and that is still out there.

Female Speaker: Jane is still trying to choose someone to do that.

**Female Speaker:** Okay. And then, the ELP-ILP HRC documents.

Female Speaker: I have the documents and I will pass them out.

**Female Speaker:** If you don't mind, why don't we just go one way? It will circle around and that way we can make sure everyone gets one.

**Female Speaker:** I'm passing out the HRC policy, the behavior and mental health support policy, which has to do with questions about, that came up with probis. And then the final one is what I think people had asked specifically to see, which is the essential life plan. And this is the policy for the oversight committee and what the job of the committee is.

**Male Speaker:** Kyle, could you add these to that stack?

**Female Speaker:** So it's four documents, right?

**Female Speaker:** It's three documents that just went around. There is an open action item for the definitions of the service types and that's what this last handout is.

Female Speaker: Okay.

(People talking in the background)

**Female Speaker:** Do you want to give an update on this document?

**Fran:** This is Fran. This final document that I will be passing around is from our wavier and it's the document that outlines all the definitions for the services we are discussing as part of this

wavier. There was a request last week to have the service definitions, so we took them right from the wavier so you know right what DDDS is working from.

**Kimberly:** Fran, this is Kimberly. Are all of these on the department's website or can we get them electronically?

**Fran:**I will send them to Libby electronically Kim, so you will be able to get them, and maybe the minutes and attachments can come along as well. The policy is on our website, but to make it easier, so it's not like an Easter egg hunt, I will make sure Libby has copies of everything.

**Female Speaker:** And I will send those out with the notes from the meeting.

The next few open items were topics that we wanted to put out there to discuss at a future meeting. So, Fran, did you have anything else?

Fran: No. I was finished, thank you.

**Female Speaker:** Did anybody have anything else they would like to discuss on this list before we keep going? Okay.

So, next on the agenda is to continue reviewing the combined assessment document that we started last week. What I would like to recommend, this is Libby, what I would like to recommend is that we continue where we left off last week, continue to go through the remaining items, and then go back to A and B that we skipped last week. And hopefully we will be able to get through all that today. And if we do, I will try to take what we have agreed to at this point to put on the Delaware assessment, I will take those and create that new document, so we can look at that during next week's meeting.

If we have time after we get through this document, we can go through to see if there was anything else from the items we covered last week that anyone else wanted to discuss or review or go through.

So, last week we made it through to page 18, N. And again, we will go through to the end and then go back to A and B, and then we will follow up with J, K, and L, where the eviction and contract items, so we will look at those as well.

**Kyle:** This is Kyle. Just as question, sorry I wasn't here last week. The ones that are highlighted in yellow, what is the reason?

**Female Speaker:** Those came from the document that we initially reviewed.

**Kyle:**South Dakota?

Female Speaker: No. That DDDS needs to complete. It's the HCDS Basic Element Review

Tool. Pages 9-13.

Kyle: Thank you.

**Female Speaker:** I took those and highlighted those because it seemed like all the questions kind of related back to those high level questions. The questions marked as exploratory questions came from a document that was distributed at our first meeting, called exploratory questions, state assessment of residential settings. I took these exploratory questions and then the few state documents that we had received, and took those questions and tried to put them in where it was appropriate based on the basic element document.

I will mention it again. I tried to do that as best I could, but some of the questions kind of related to multiple questions, multiple topics, so, if they are in there multiple times or as we are going through these if you see a question that relates to a different question more appropriately, we are free to move things around, change, add, edit, these questions.

We are going to start with N as in Nancy, at the bottom of page 18. Does somebody want to start by mentioning what they liked about any of the items under N? If not, I will start. I liked the exploratory questions. The exploratory questions on 18, and the top of page 19, I thought were appropriate.

**Victor:** This is Victor. At the top of page 19, I like where questions are phrased as in the case of D, do staff or other residents always knock and receive permission, but at the bottom of page 18, in A and B, for example, it says #(Inaudible 12:02), it says can all individuals. They are taking that step in the case of that question on page 19 for example, but not to the bottom of page 18.

**Terry:** This is Terry. I'd like to go with the same ones Libby.

**Libby:**So, it's can all individuals living at that residence, is that what you mean? And that includes people receiving services and staff?

Victor: People receiving services. I just think the answer is more valuable that way.

**Libby:**But it's individuals receiving services, not...do we need to put that in there?

**Terry:** This is Terry. I just wonder if it shouldn't be an assumption that individuals as used within the documents refers to the consumer.

**Libby:**Okay. Is that okay with everybody if we change those two to all individuals? And A, B, and C, on page 18? Are we in agreement?

**Tim:**Well, Libby, this is Tim. I have trouble with these kinds of things because you have a lot of folks out there in residential facilities who would not be a good thing to be able to have them lock people out of their room. I don't know how some of the other states have done this, but if

we include these, which I'm fine with doing that, but for instance, A, can the individual close and lock the bedroom door. Yes/no. If no, then why? I think we need some, we need to allow the provider the ability to explain why it's a no situation.

**Libby:** This is Libby. I agree. And I think, as I have been going through these questions, I have been thinking of my own daughter, and I think all these questions, many of these questions might be okay to ask, but the options for the answers have to give an out for somebody who needs staff to be able to come and go for whatever reason.

**Terry:** This is Terry. I think that applies to most of these assessment items we have gone through, that there should be an opportunity to explain, and I think particularly with respect to rights, we all know there are situations where issues may necessitate some restrictions of rights and I think providers are going to have to explain those restrictions and the rational for them.

**Libby:**Right. This is Libby. If it's okay Tim, I think that discussion, we can continue that discussion with the answer responses, when we get to that point. Last week we started reviewing this and I mentioned that I didn't include answer responses in this document because I thought if we focused on the questions first, then we could go back and kind of think about the answers.

**Tim:**I do think, this is Tim again, I do think N is a totally appropriate question to ask. It seems awfully obvious. But provider/owner control the setting provides units with lockable entrance doors. I would hope so. So, that is one that I would include even though it is very obvious.

**Kyle:** This is Kyle. When we do, when we are talking about restrictions of rights, that throws up a red flag to me. I understand the questions, but, until we come up with a final way that is going to be addressed, I just want to, I'm just kind of wary of that. I think it's going to have to be framed very well or questioned very well when you are talking about restriction of rights.

**Libby:** Absolutely. I agree. This is Libby. And I think that's why I kind of tabled that separate from the question because I think that will be a discussion that will be kind of lengthy that we need to have.

**Lisa:** This is Lisa. I have one question. In this restriction of rights, I hear what Tim is saying, we have a lot of folks, our doors lock, they have the capability of locking, all the doors for privacy, but many people choose not to, for whatever reason. So, are the asking if the doors are locked, they have the ability to lock for privacy, but some of them chose not to, so it's not necessarily a restriction of rights. Does that make sense?

**Terry:**One way of addressing that, this is Terry, might be to say, does the individual have the option to close and lock the bedroom door.

**Lisa:**Right. Exactly.

**Terry:**If we wanted to change it along those lines.

**Libby:**So, do all individuals have the option.

Terry:Or opportunity, whichever.

**Victor:** This is Victor. I think opportunity is a better way of putting that.

**Libby:**So, A would be, do all individuals have the opportunity to close and lock the bedroom door. The same with B.

I brought a different color pen this time to make it easier to figure out which ones we agreed on.

So, we are saying A, B, and C.

And the second page, #3.

#(Inaudible 18:13)

**Female Speaker:** No, we are not going to add C, right, just for A and B.

Libby: C is as is.

**Kyle:** This is Kyle. If you look at page 19, on that issue of the option or opportunity, Pennsylvania, in the middle, uses the word freedom, so there are various ways to do it.

**Libby:**And I was thinking we would just make a note on the white board or piece of paper up there the ones we are agreeing to. So, Carol, if you could do, N as in Nancy, exploratory question #2, EQ2. A, B, and C. And exploratory questions #3. Are those different enough from the other three or do we want to include those too? Does anybody have any comments on those two? I would like to include those two as well.

**Tim:** This is Tim. I would agree with that.

Male Speaker: Terry. I agree.

**Female Speaker:** Kathy, I have a question about D. Aside from bedroom and bathroom, what other living space would we be discussing in like a group home setting.

Male Speaker: The common areas.

**Female Speaker:** Knock and receive permission to enter a common area?

**Male Speaker:** No. I mean what it's saying there is that staff know and other residents know to knock and receive permission before entering the individuals private space, i.e. their bedroom.

But that doesn't need to be asked with respect to common areas. Maybe I didn't understand your question.

**Female Speaker:** Okay. I'm looking at D. It says entering an individual's living space. We looked at C, which talked about entering a bedroom or bathroom. I'm just asking what is this living space we are referring to.

Male Speaker: We might want to change it to bedroom. That's probably...

(Everyone talking at once)

**Female Speaker:** I think C says the same thing.

**Libby:**If we are looking at all those different, residential options, maybe it's knocking on somebody's door to the apartment before they walk into the apartment or, if it's supported living.

**Lisa:** This is Lisa. Even for all of our programs, you should always knock on the front door before entering their house.

**Libby:**Right. And I guess that's what I was thinking when I read this question. Kind of like the front door.

**Lisa:** This is Lisa. I have observed that the staff always ask even if the door is wide open. They knock and say, is it alright if I come in. It's routine. They don't just walk in.

**Victor:** This is Victor. On #3 again, when I see the individual has privacy, I just think the answers will be more valuable if it's phrased, do all individuals have privacy in their living space. It's just like the next question, on 6, does the client have a key to the home. I think that and all questions like it should be do all your clients have a key to the home, and then, to Terry's point on the other issue we discussed earlier, if the answer is no for this person or that person, then an explanation can be provided.

**Lisa:** Does everyone want a key to the home?

**Terry:**Well, I think, this is Terry, there are times when people won't hang on to keys and lost them. There are many circumstances that can arise there.

Libby: Okay. So going back to 3D.

**Lisa:** You can combine 2C and add a line to that. Knocking to the front door as well as...

Libby:Bedroom and bathroom.

**Terry:** This is Terry. You might also put bedroom, bathroom, or other private space, if somebody

does have that, then you've got all the bases covered.

**Libby:**Or other private space. Okay. So, we are changing 2C on page 18, do staff or other residents always knock and receive permission prior to entering a bedroom, bathroom, or other private space.

So, let's see, 3E. Just with revisions. For A, B, and C, with revisions. 3E, does staff only use a key to enter a living area or privacy space under limited circumstances agreed upon with the individuals.

**Kyle:** This is Kyle. That goes with what Victor already said, all individuals.

**Libby:** All individuals. Is that a question we want to ask though?

**Kyle:** This is Kyle. I think so. It kind of goes to your point though on the others, if no, why, but I don't think it hurts to include that.

**Victor:** This is Victor, when I say questions phrased that way having more value it's so that there wouldn't be an opportunity where a provider could answer yes or no and the provider might mean most, but not necessarily all. And if we provide the opportunity to say why not with follow up questions, then I think we are covered.

**Libby:**Okay. So I think I'm hearing that 3E will stay with the change of agreed upon with all individuals. So, 3E, Carol, with revisions. EQ3 with revisions. Are there any others on that page 19 that anybody thinks are different than the ones we have identified?

**Kyle:** This is Kyle. The one about having a key to the home.

**Libby:** Does your client have a key to the home? Specifically that one?

**Tim:**Libby, this is Tim. I'm just curious from providers, for instance, the Salvation Army, is this normal to give keys out to...

**Female Speaker:** If they ask for it. We have, I have, the majority of my folks are much lower functioning and more fragile and have no interest in a key. You know what I mean? Some of my individuals that are higher functioning that have asked for a key, they absolutely have a key, not that they use it, they just want to have a key to their house and have at it. So, if they ask for it, they can absolutely have a key, but I would say 90% of my folks don't, based on their functioning level.

**Tim:** Yeah, my son would fit into your 90%.

**Victor:** This is Victor. For the higher functioning people that you mentioned, would they know they could ask for a key?

Female Speaker: Yeah. Oh yeah.

**Terry:**This is Terry. I think the thing that often plays into that is whether or not the person has time alone in the house without supervision. Some people may come and go at times when staff is not present.

**Female Speaker:** Some of ours have a key just because they want to have a key.

**Kyle:** This is Kyle. As a follow up to Victor's point, maybe that's an additional question you want to put in there. Are they aware or is there a policy or written language that they have access to a key?

**Female Speaker:** Which I think is a better way to do, instead of saying do all of our folks have a key, because I think the majority of our folks don't, but are they aware I think is a good question.

Male Speaker: I think you could have both.

Female Speaker: Yeah.

**Libby:**So, Hawaii 6A, do all clients have a key to the home and the follow up question would be...

**Terry:** This is Terry. You might want to combine them to say do all of the consumers have the freedom to have a key to the home as desired?

Female Speaker: I think that dilutes it too much.

Terry:Does it?

**Female Speaker:** Yeah. I do. It's like, if they think about it and know about it, they might ask for it. I think that's putting too much on them.

**Libby:**So, two questions?

**Female Speaker:** Hawaii right? I'm sorry.

Libby: Yes.

**Female Speaker:** I think access to a key is fine. If you want to qualify it like that. I think the norm should be to have a key, and then if they don't have a key, the reason why they don't have a key.

Male Speaker: I would think access by itself isn't enough. You also have to know that you have

access to it.

**Kyle:** This is Kyle. I don't know if you still remember, we were thinking about adding a question about access. Are they aware that they have access to a key? That would be one. And then, do they have a key. If not, maybe why.

**Libby:**So, do individuals know that they can have access to a key.

Male Speaker: That's good to start.

Female Speaker: You want to ask both, right?

Male Speaker: It's about access, it's about if they have one. Maybe if they don't, why.

**Kimberly:** This is Kimberly. Quick question. So are we saying that if they don't have access to a key then that place is not in compliance with the CMS rule?

**Libby:**No. Kind of like with the other questions, we will have to have a separate discussion on the answer options and it's not just yes or no, it may be yes with other circumstances or policies or person centered plan or ELP or something like that.

**Kyle:** This is Kyle. And I think it's going to be again up to CMS to determine what is in compliance and what's not. That's not for us to decide.

**Kimberly:** Yeah, but CMS isn't reviewing the assessments, the division, isn't the division making the call on...isn't this group supposed to give the recommendations on stuff like that?

**Kyle:** This is Kyle. Then it would be the division that makes that.

Laura: I think going back to what I said before, this is Laura, that the norm should be there's a key. If the person doesn't have a key, there's a good reason why the person doesn't have a key and then they document it. Which is what's going to happen with a lot of these living issues, where it's, the expectation is you have a key, but if there is a good reason, a safety reason or whatever why the person can't have a key, there is a reason why that happened. But going in, everybody should have a key. Conceptually, everybody should have a key, but if somebody can't have a key, there is a reason why the person doesn't have a key.

**Libby:** This is Libby. Back to the original basic element review tool, that I believe DDDS is going to have to complete. The answers are yes, partially, explain, N/A, explain, evidence, and no. I think when we get to that point we will have similar answer options that will cover that. So, back to these questions. We are going to make two questions out of this. Can somebody rattle off those two questions? Kyle?

Do individuals know they can have access to a key? We will start with that.

**Female Speaker:** I think you should ask the question do they have a key first, then do they know they have access.

**Kyle:** This is Kyle. Whatever process you want to do, I was just hoping to include all ways.

**Libby:**So, the first question Carol, Hawaii 6A is in. Do all clients. Then, we are adding a new one under Hawaii. Do they know they have access to a key? They can access. You have to write that one down. We are good with that one. Anything else under N to include? If not, we will move on to O.

The setting provides individuals who are sharing units with a choice of roommates. Before we start, Melinda, do you want to introduce yourself for the recorder?

Melinda: Hi. Yes. This is Melinda South from (?). Thank you.

**Libby:** And do you want to tell us what you like about N, or O? Anything under O? Put you on the hot spot.

Female Speaker: I thought four was fine. It encompassed most of it.

**Victor:** This is Victor. I would just add the word all before individuals.

**Melinda:** And not roommates, but housemates. This is Melinda.

**Libby:**Is it both?

**Terry:** Yeah, that is a good question. This is Terry.

**Melinda:** This is Melinda. I don't know if we have, do we know if there is anybody in the division who has residential services where they share rooms?

Male Speaker: It's becoming pretty rare.

**Libby:**If somebody is married?

**Tim:** This is Tim. I have never seen in a group home or apartment that situation.

**Fran:** This is Fran. It is rare. We are really tight on emergency placements right now, so in an emergency someone might have a roommate, but it wouldn't be for a long time. It would just be until the crisis has passed.

**Libby:** This is Libby. Should we change that to roommate/housemate?

**Tim:**This is Tim. I think that is good.

**Kathy:** This is Kathy. Then doesn't that change the way the question is? If you are looking at this as the possibility of the person having a roommate and you are looking at these questions about sharing a room, that is very different than sharing a house.

Male Speaker: It is.

**Kathy:** You can't really ask the same question.

**Libby:** This is Libby. If the real question is choice of roommate, then we should just focus on...

**Lisa:**Pennsylvania says how many participants at this location share a bedroom, then, do participants who share a bedroom have a choice of roommates. So, I think they are asking about the house.

**Male Speaker:** Where is that at?

**Lisa:**Pennsylvania. Page 5.

Male Speaker: Right in the middle.

**Terry:**No. I mean, this is Terry, I think that's asking first of all, are there shared bedrooms, and if there are, do the people who live in them have a choice of roommates. I don't think they are talking housemates there.

**Libby:**So, do the exploratory questions at the top, if we just focus on roommates, I guess the first questions is Pennsylvania, do participants...

**Lisa:**I think #(Inaudible 34:14). If you look at exploratory question for #3, does the individual express a desire to remain in a room with his/her roommate, that is clearly talking about a room, not a house.

**Libby:**So maybe the first question should be does anyone have a roommate, if no, move on, if yes...

Female Speaker: Correct.

**Libby:**So where is that question? Is that already in here? So, we will add a question.

**Kyle:** This is Kyle. Does anyone have a roommate, Libby, then, if not, if so, then you would go on and answer these others.

**Libby:**So, we are adding a question, Carol. Does anybody have a roommate and then we are

keeping all exploratory #4 bullets. Is that correct?

**Tim:**This is Tim. Are we going to deal with the housemate issue then?

**Lisa:**I think that's got to be somewhere else on there.

**Libby:**Is that under B maybe?

**Terry:** This is Terry. I'm not sure it's in there.

**Libby:** Independence when making life choices? Would that fall under that? No? Do we want to include a separate section under this one for housemates?

**Tim:** This is Tim. I think we definitely need the housemate question in there because that's the way it is in most of our residential facilities. Connecticut, further on, does use the housemate term, but it doesn't deal with this particular issue.

**Kyle:** This is Kyle. Where is that Tim?

Tim:Page 23, Connecticut 7.

**Laura:** This is Laura. I think it's important if the questions reflect practices in the state, and these FEMA prompts are based on questions, so feel free to expand on the questions. Is it 6? The case study? I don't know what the practice is in terms of how people are assigned apartments. I don't know how this is currently done.

**Fran:** This is Fran. This goes back to a comment that Tim continues to make, and that is, we expect to see differences in what the practice used to be, and what the intention is for the practice to be. So when this tool is completed, we are not expecting deficiencies in terms of, no we don't do this. We are expecting a self-assessment in, we stopped doing this at this time, or we don't do this at this time, however, we are in the process of changing this practice, and as of this date, you can expect us to be doing this. This isn't, I would consider looking at it as a process, not so much as where my team goes in and you get dinged for things. This is more thoughtful. No, we don't do this. We have been talking about this and this is what will happen as we move forward.

**Kyle:** This is Kyle. That's very well said, and that is really the process throughout this whole process. We should keep that in mind.

**Lisa:**If you look on page 7, C, the setting facilitates individual choices providing services and supports and who provides them. That is where it's talking about was the individual given a choice regarding where to live. That is talking more about choices.

**Libby:**Okay. And we didn't get through C.

Lisa:I think when we go back to that we will see it.

**Libby:** Just because that question is there, that doesn't mean...

**Lisa:** But there are a lot of probes. I mean...

**Libby:**Do we want to look at those now?

**Female Speaker:** What page are we on?

Female Speaker: 2.

**Fran:**It could just be that we are coming to them.

**Lisa:**This is on page 7.

(Everyone talking)

Female Speaker: No, we didn't.

**Tim:**This is Tim. I suggest we go back to the exploratory question and do a second one. It would read something like this individual has his/her own room and, no that won't work. This individual has choice of roommate/roommates. Then, you could ask, does the individual, I'm sorry, housemates, I'm try to get back to housemates here. So, does the individual have choice of housemates? Does the individual talk about his/her housemate in a positive manner? Does the individual express a desire to remain in the house with the housemate? Those questions can be redone in that format.

**Female Speaker:** Could it be housemates? Plural?

**Tim:** Yeah, it could. Housemate or housemates. Group home it's plural, but my son's situation is singular.

**Fran:** This is Fran. I don't mean to interrupt the process, but Dr. Macy is here. I just want to make sure everyone knew Dr. Macy. Dr. Terry Macy, he is our new director of community services. While I am gone and as we move through the processes, if there is any questions, or any processes that you would like some more information, Dr. Macy would be available to assist you and he will be working with Eddie to get any information that you need.

**Male Speaker:** #(Inaudible 40:18) We have been through this and had a great time. Our application was submitted and we are hoping that will be approved and we will move on. Doing good work and I support that.

**Kyle:** This is Kyle. Then we should just use all Connecticut questions. (Laughing)

**Tim:**This is Tim. Terry, do you know when you will hear about whether Connecticut's is accepted? That would really give us some guidance.

**Male Speaker:** I know. I stay in touch with our Medicaid director. Every time I ask her, she looks at me and goes...

Male Speaker: Nothing yet.

**Male Speaker:** Jane has probably shared with you that the upper structures of CMS are completely obliterated with retirements, so it's pretty #(Inaudible 41:12) Image the impact that is having down the line. As you know, they have all the states submitted and it's a wonderful resource.

**Female Speaker:** Has Delaware been added to that list yet? Cause I noticed it was not on any list last time I looked.

Male Speaker: It won't be added until you get this. I'm sorry...

**Female Speaker:** It said one list was approved and one list was submitted. The transition plan. What were you referring to?

**Male Speaker:** No plans have been approved yet. What #(Inaudible 41:41). What they have is the states who have submitted and I think Delaware was on it. It's a very slow process at this point and I think the whole world is waiting to see, just get one out there so we can read it.

**Libby:** This is Libby. You said Connecticut's was submitted. What, the transition plan? Or the...

**Male Speaker:** The transition plan. We already did the questions. We have been through that part of the process. Several states haven't. Then, Connecticut was in a different kind of place. I think seven states were in a box that CMS created. If you were creating a significant change in the process, then, you were obligated to submit the plan within 180 days. So, we had to make it, we weren't given any choice. #(Inaudible 42:45) Agencies that were taking the full year were going to be looked at differently. We thought ours was a pretty decent package. We are very much waiting to see what the word is. Thanks.

Male Speaker: Thank you.

**Victor:** This is Victor. Looking at exploratory question 4 on page 20, the second bullet, does the individual talk about his/her roommate in a positive manner. How would the provider have the information to answer that question correctly?

**Tim:**This is Tim. I can answer it for you by personal circumstance. My son's apartment mate criticizes him brutally all the time. He loves it. He loves the attention. He doesn't care if it's

negative or not. And the staff all listen in. They know exactly what is going on. All the direct staff is on top of that issue. They can tell you who gets along and who doesn't. That has been my...

**Terry:** This is Terry. You will have a lot of housemates who are non-verbal. Not that that negates the question.

**Victor:** This is Victor. That is part of my point that some may be non-verbal, but I know of any number of people who are extremely verbal who none the less do not like to wear their opinions on their sleeve, positive or negative. So this question again, it goes back to some of the questions we discussed in previous weeks, where I think the greater value would be this question asked of the individuals, rather than the service providers.

**Lisa:** This is Lisa. You obviously haven't met most of our residents, cause those that are verbal, or non-verbal, that are unhappy, they let you know when they are unhappy. We have had several over the years request moves because they haven't liked their roommates and have moved.

**Libby:** This is Libby. The question is do they have a choice of roommates, not are they happy with their roommate. So maybe that bullet isn't appropriate for this question. If it was an individual assessment maybe it would be appropriate, but...

(People talking all at once)

**Male Speaker:** I think that bullet is really appropriate. My son loves his roommate. That is so important to his life. So I would definitely keep it in.

**Kyle:** This is Kyle. There is no downside to keeping it in, as long as you include it in the individual assessment also. It should be in both. #(Inaudible 45:35)

**Libby:** This is Libby. The last bullet there is very important as well, that if they don't like their roommates, that they know how to change roommates.

**Terry:**Well, I think that, that last bullet, this is Terry, is going to have to be changed to all in keeping with Victor's suggestion. Individuals know how he/she can request a change in housemates or their home. I don't think it's always a matter of if I don't like a housemate that person is leaving. That is just not the way things work. So it may be a matter of either that person does need to leave for whatever reasons are apparent to the provider or others, or the individual themselves may want to choose a different home or housemates.

It will also bring up some procedural issues and I think within homes that I have operated in more recent years, we had the opportunity for individuals living in a home to meet a new person who has been referred, who may have chosen to live there, to give feedback on that person. But I think these issues are suggesting there would need to be some formal procedure for not just that individual to choose the home and housemates, but for those housemates to accept or chose that

individual as well. So there is some significant implications here I think.

**Libby:**Okay. So let me see if I can summarize this so we can move on. So, the first question that we will ask does anyone in this house or apartment have a roommate. If yes, we will ask the bullets under #4. We will just throw in all those bullets for now, and then we are going to take a look at this again anyway.

In addition to that, we are going to ask a question regarding do the individuals have a choice of housemates and do the individuals have a choice in their home. I think that might be under another question as well, but I will add that in there and we will take a look at this again.

**Kyle:** This is Kyle. If they answer yes to that, then they...

**Libby:**If yes, then they will ask another version of those bulleted #4 questions and I will change all individual to all individuals for those question.

**Terry:** This is Terry. This may or may not work, but one iteration of that question might be is there evidence that each individual has the opportunity to choose his/her housemates. Someone may have a better way of stating that.

**Libby:**Okay. I will go ahead and include all of that. When I redo this, we will take a look at all of this again and we can revise it as needed. Are there any other ones under O?

**Kyle:** This is Kyle. Tennessee 31. I think is the question.

**Libby:**I think it is as well. I think that falls under independence and access to...yeah. It's under there a couple times. It is physically accessible and do they have access, there is another one. Making life choices. I think that may be better under another one.

**Male Speaker:** What page is that on Libby?

**Libby:** 20. On page 20 is the one Kyle is talking about. Tennessee.

**Male Speaker:** Yes, but you said it's included somewhere else?

**Libby:** Under S it's talking about physically accessible.

**Terry:** This is Terry. I think you are talking about two different things. One is I think freedom to access all aspects of the home, for lack of a better term, and the other is physical accessibility. Does that makes sense? There are times, for example, when you have an individual who is not safe near cooking food, for example. And because of that, the provider might document the fact that they put up a gate and supervise that person to prevent them from harming themselves.

**Libby:** I agree. This is Libby. But it doesn't have anything to do with having a roommate. Which

is the one that we are on right now. You will see that question numerous times through the next couple of pages too.

**Kyle:** This is Kyle. That's fine. If it needs to go in a different area, that's fine. Terry makes a good point. Having the freedom to do, and having the access. We can work on wherever that is appropriate.

**Libby:**It doesn't work as well with that one.

**Terry:**This is Terry again. By the way, I think I mentioned this previously, without a second egress from the basement, for example, the fire marshal prohibits people from going into the basement. I'm pretty sure. Isn't that right Mickey? Mickey has put in second egresses to some of her homes.

**Kyle:** This is Kyle. Why?

Terry:Safety.

**Tim:** This is Tim. We had to do it when we built a room down in our basement. It's done town by town, county by county, the laws are not uniform throughout the state, so you can't make a blanket statement about it. But if you are going to have people downstairs, you have to be careful about two egresses. It cost me a small fortune, but...

**Female Speaker:** #(Inaudible 51:40)

**Tim:** This is Tim. I desperately want to move on. I just like P. I think P is good. I would like to hear from people leasing property. I'm sure there is some regulation in the lease agreement about this kind of thing.

**Libby:**So, P has to do with the freedom to furnish and decorate sleeping and living units.

**Lisa:** This is Lisa. We lease all properties. We don't have any restrictions on decorating or doing anything. We have never had a problem.

**Tim:**This is Tim again. I would imagine apartment complexes must. They probably have certain paints they will allow and that kind of thing. For CLAs it's probably an issue.

**Laura:** This is Laura. I would say, it's usually an issue when you move out. You can do whatever you want as long as you put it back when you leave. If you don't, then there may be an issue.

**Libby:**So, if we look at the next page, page 21, exploratory questions five, I kind of like those three bullets to start with. Individual's personal items, pictures, furniture, linens, and other household items. Does anybody oppose including those three? All individuals?

We are on P, exploratory questions 5. 5, three bullets. I don't know about the first two bullets on page 20, if anybody has any thoughts on those two.

**Terry:** This is Terry. I don't think they have anything to do with, well, the small group conversation thing, that seems kind of trivial to me, but the other one doesn't have anything to do with furnishing and decorating, but that is just my thoughts.

**Libby:**So that might go back under the topic of privacy, that first bullet there, as furniture arranged.

**Male Speaker:** If we didn't already have it down.

**Kyle:** This is Kyle. Are you looking at exploratory question 2? Sorry. That looks like privacy, but things with the locked bedroom and bathrooms before.

**Tim:** This is Tim. I agree with Terry on that next one. Is the furniture arranged to support small group conversations. I don't think we need to include that in the self-assessment.

**Libby:** Any other ones outside of those first three bullets?

**Laura:** This is Laura. I kind of like not having being so, I prefer a more open-ended question and that is, is it arranged the way the individuals prefer. That is Connecticut 33. There is some ability to arrange the furniture in a way that suits the people that live there, right? Not like, is it conducive to small conversations, that is kind of a silly question. But are they able to decorate it or arrange furniture in a way that suits them. Which is what Connecticut 33 is asking.

**Victor:** This is Victor. I'm okay with that question, but I would also like to see a question like that asked of the individuals in a separate assessment.

**Lisa:** They are allowed to decorate to a point, as long as beds are not blocking the windows, they can't...

Male Speaker: Fire egresses.

Lisa: Yeah, the fire egresses. They can't have things in front of the heat register.

**Libby:**Okay. So we are going to include Connecticut 33. Anything else before we move on? Next one is Q? Freedom and support to control their schedules and activates and have access to food at any time.

**Tim:** This is Tim. I want some provider help again. I am always looking at you guys here. Meal time. How is that done in the typical group home?

**Lisa:** Well waking up time is more. Schedule for waking. They all go to day programs. They

have to go to DART, so they don't necessarily have their own flexibility Monday through Friday. Weekends are different. All bets are off. They can sleep in as long as they want. They can do whatever they want. That is the same thing our population does. We have to get up for work and all that. Meal time, they eat when they want. If someone doesn't want to eat at a certain time, they can eat later. If they don't like what's on the menu, we can fix them whatever. We are very lax with that. We have to follow nutritional guidelines and menu's because believe it or not we still have to write down a menu sheet of what everyone eats at every meal. Welcome to 2015. But, they do, they can make substitution. Food at any time. That is the catch all. We are, if our people gain weight, it's our fault. We have nutritional assessments that say these people can't eat, not everybody, but these individuals cannot eat after 7pm. We have people that are diabetic and have lost a lot of weight because of the guidelines. Eating at any time, for health reasons, obviously, you know, not because we are controlling.

**Male Speaker:** But that is a restriction that is something you can justify.

**Lisa:**I wouldn't say it's even a restriction. It's in the nutritional guidelines or from the doctor.

Male Speaker: It's a restriction.

**Lisa:**Right. But not a restriction that you have to go to HRC for.

**Male Speaker:** In my agency it was. I had my own HRC.

**Fran:**This is Fran. Anyone of us at the table could have been told by a doctor that we have to restrict our diets in some way and we get to choose if we want to. If somebody wanted to push it, it could very well be an issue.

**Lisa:**It's not like we don't have snacks that they want. We are, we do have regulations that we have to follow from their doctor. Because it comes back to us if they gain weight, then we are doing something wrong. If their blood sugar is high. You are damned if you do and damned if you don't.

**Kyle:**This is Kyle. I doubt if...

**Male Speaker:** ...individual plan or something.

**Lisa:** Well, it's in their medical records or in their nutritional assessment or something of that nature.

**Kyle:** This is Kyle. I think Fran makes a very good point, and to her point being said earlier, in that, it's not just what is happening now, but what should be happening to comply and I kind of understand everybody's point here, and maybe if there is something like we have had before, if they are not allowed, then why.

**Victor:** This is Victor. I agree with Kyle. I think the foundation that CMS is looking to impose here is that there is a choice, and then, if there need to be limitations, medical or otherwise, then we provide that explanation.

**Libby:** This is Libby. It's the otherwise that concerns me. I mean, as a guardian of someone living in a group home, I don't want her eating whatever she wants, whenever she wants, because she will eat ice cream all day every day. That is not a medical, that is not coming from her doctor. That is coming from her guardian. So, is that...

**Male Speaker:** Isn't that a basic human right to eat ice cream all day, every day? (Laughing)

**Libby:**I would like to do that.

**Victor:** This is Victor. I agree with...(Laughing)

**Kyle:**But that's why you can have that if not, why. Then, it's determined later.

**Libby:** Yeah, but is that acceptable?

Male Speaker: I don't know that.

**Libby:** That's what we are going to have to talk about.

**Male Speaker:** There is always going to be reasons that most rights have to be restricted and it comes down to being able to justify that if there is a legitimate reason.

**Fran:** This is Fran. Again, it's going to be different facility to facility. There may be a facility where someone can say to someone, your doctor has said it's probably not good for you to be eating so much ice cream, can we maybe decided to save the ice cream for dessert, instead of having it for a snack, and somebody might be able to say okay, and somebody else may not be able to say that. I think it would be individual to individual and facility to facility. One of the concern for me in terms of scheduling that we are dealing with right now that I think is more pertinent is that we have a good bit of our work force is old enough to retire, and are still going to day programs because it's convenient for providers, versus having someone stay home all day, because they are retirement age and they want to stay home all day and watch TV and do what other people do when they are retired. That is more of an issue for me than whether or not people can get ice cream, whether someone said they could have it or not. I think you could easily be able to say, no, but here is the reason why.

**Lisa:** This is Lisa. In defense of providers, you have only been on the scene two years, and we have had people who wanted to retired for several years and DDDS always says no. When we try to say they want to stay home, they have to explore this option and this option. I do have two gentlemen who are finally retired and have been for several years, but we had to go back and forth and we still, they still said no. Even six months ago, he doesn't want to go anywhere. That

has just changed. I don't think it's an inconvenience.

Male Speaker: It's financial implications.

Lisa:But if they give us the support for that individual. We would like them to be able to...

Female Speaker: You have enlightened us.

**Laura:** This is Laura. I know I only know anecdotally from people telling me, I have never seen the policy, is it a requirement that a person who is in a residential placement have a day placement?

**Terry:** This is Terry. It's certainly an expectation, if it's not a requirement.

Laura: Whose expectation?

**Terry:**DDDS has been my experience.

**Fran:** This is Fran. I think in order to be able to justify participation on a waiver, certain things have to happen. However, I will say that as Lisa just said, I think in the last couple years we have been changing that mindset and that if individuals just do not want to go somewhere, they don't have to, and we do have individuals right now who do stay home.

**Female Speaker:** I shouldn't have to point out the irony of it all. Right?

**Fran:**So, but since we have been looking at choice and what choice means, we do have individuals who don't have activities during the day, and some, unfortunately, can be pretty destructive during the day. It would be better for them, but their choice, or their guardian's choice, is for them not to, so...

**Kyle:** This is Kyle. And don't these rules, or guidance kind of lean toward that choice.

Fran: Yes. I would say yes.

**Female Speaker:** Staying home?

**Fran:**Well, if somebody chooses or their guardian chooses that there is a reason for them, or they just don't want to do anything, or they are not successful in a day program, we are, the more likely scenario is that somebody is going for unemployment and they really aren't interested in working. They don't want to go to the pre-employment program. Do they have a choice to not work? If the answer is yes, do they have to go to the pre-employment program? If not, are there other options they might enjoy and if so, what are those? What other options can you offer that they may choose to do instead?

**Lisa:**I think for the most part we all agree that day programming and getting everyone out during the day is a good, positive thing. And they trip to get out of the door in the morning because they can't wait to get out, for the most part. But there are some in their golden years that definitely let them know they are old and they are not going anywhere.

(Everyone talking at once - 1:04:09)

**Male Speaker:** I don't want us to forget Libby's point. I spent a couple years on the HRC in Newcastle County, and I was shocked by the number of people I saw come through there who were clearly obese. 5'2" - 300 pounds for women. It was appalling and we kept talking about it on the Governor's Advisory Council. I think we have a system wide problem with obesity and one of the reason is access. I don't know how we get to that, but I think we have to be concerned about the person's health as well as their freedom to eat ice cream.

**Lisa:** When it says food anytime in bold letters, that scares me.

**Kyle:** This is Kyle. I think that aside from the population we are looking at, there is a problem with obesity around the country.

**Female Speaker:** I just wanted to say, I have a brother who is retirement and he would be bored out of his mind if he didn't go to his senior program. And one of the things he does while there is exercise. He would be miserable if he didn't have a place to go. He still calls at work. I don't know what they do without me. He has a role for himself there. He would be devastated if he had to stay home all day, every day.

**Fran:**This is Fran. So again, I think it would be a facility to facility issue, the response. They would have to look at the reasons they may have that someone would call a restriction and be able to discuss the reasons that that is a reasonable accommodation that they have to make or a reasonable restriction that they have to make based on health reasons or the request of a guardian or something of that nature.

**Libby:** This is Libby. So let's go back to the questions and I think what we are talking about is what is an acceptable answer or documentation for not saying yes is the answer. If we focus on the part of the question, freedom to support to control their schedules and activities, and let's do the food next. But, schedule and activities, if we look at the questions related to that first. I kind of like Hawaii's on page 22. Hawaii 3, the client picks the time they get up and take a bath. I would like to see where they, do they get to pick a time where they exercise.

**Kyle:** This is Kyle. Libby, were you just skipping over the exploratory questions altogether or...

**Libby:**No. It's just something I liked. I liked those two. I think I need reading glasses. (Laughing) I didn't skip that intentionally.

**Tim:**This is Tim. I like all those exploratory questions. I think they really get at our issues. 5, 7, and 8.

**Female Speaker:** This is (?). I agree with that. #(Inaudible 1:07:31)

**Libby:**So all of exploratory questions, 5, 7, and 8. This is Q. Exploratory question 5, under Q. 5, 7, and 8. All bullets.

**Kyle:** This is Kyle. I like Hawaii too. The ones you mentioned.

Libby: Which kind of goes back to some of the...

**Male Speaker:** I think it's embedded in those. And those are perhaps some of the most important activities, but they are not all inclusive.

**Libby:**Can we include Hawaii 3, all of those and just take a look at it again. Can we move on to R? Or anything else under Q?

Is Connecticut 7 on page 23, is that separate, is that kind of different from the other questions?

**Male Speaker:** This is what Tim was talking about a while back with a housemate.

**Terry:** This is Terry. I think it's pretty comparable with the second bullet in exploratory question 5.

**Libby:**Okay. As long as it's covered. So, are we okay to move on to R. Visitors at any time?

**Female Speaker:** This is a little different though. #(Inaudible 1:09:18) It has nothing to do with their choice. It could be just because they are at a day program or the bus comes at a different time.

(Everyone talking at once)

**Female Speaker:** Connecticut 7?

Female Speaker: Yeah.

Libby: Again, I will put the ones we are agreeing to on a different document and we can look at

it again.

**Kyle:** This is Kyle. Before we go to R, Tennessee 36, the very last question there, is that something that is a little different than some of the other things. Curfew and scheduled returns. Something we might want to include?

**Tim:** This is Tim. Providers again. Curfews, is this typical? I've never heard of it. It may be a non-issue.

**Fran:** This is Fran. This is another question where there may be an individual in a facility where there is a curfew, but it's a curfew that has been agreed upon with input from a family member or guardian for some reason. So again, it's a facility to facility based question.

**Libby:** This is Libby. I wouldn't mind including that, just that first question. And our answers will be come up with at a late time. Tennessee 36.

**Jamie:** This is Jamie. Fran, do a lot of these rules #(Inaudible 1:11:08). Do they get together and make house rules? There is a curfew? Their TV time. They agree to a menu.

**Fran:** This is Fran. There are times when that happens and as long as the people sharing the home are in agreement that we would like to eat together at this time, or we are in agreement that we would prefer not to have visitors after 10pm. As long as the individuals have decided that as housemates, that those were the rules of the house, that would be fine.

**Jamie:** And do any of these address house rules? I haven't heard that. As agreed upon for the whole house?

**Female Speaker:** The thing with house rules, #(Inaudible 1:12:56) You could get people evicted for violations of house rules. It seems like something like who they want to eat with shouldn't be a house rule that you could be thrown out of your house for.

**Fran:**This is Fran. Well, maybe not who you want to eat with, but we would all like to eat together at 6pm every night, but I won't be coming in til 7pm, so that's okay with me as long as I can eat a little bit later. If the individuals living in the home decide they want to do things as a group, and they set certain time parameters, that is acceptable, because it's the people who live in that home, it's their choice, who they eat with and when they are going to eat. Now, if they are not all in agreement, you can't establish a rule that we are all going to eat at this time if everybody decides they want to eat at different times. That is just negotiating with roommates how you are going to get along together.

**Melinda:** This is Melinda. The house rules that we establish, many of them don't cover what to eat. Most of it is privacy, as well as when people do come in and when they bring people in. Having overnight guests on weekends. Things of that sticking. There is no essential consequence to it, other than roommate to roommate, and then maybe meeting with a case manager on the fact that I'm not happy because you are bringing people home at 2am. It's sort of like conversationary.

**Fran:**This is Fran. We are struggling right now with some facilities that you have maybe not a curfew, but a set hours where visitors can no longer visitor and the individuals living in the house are not in agreement with that. That is a different scenario than if everyone in the home says, you

know, we would like to walk around in our pajamas after 7pm or 8pm and relax downstairs and we would prefer not to have any visitors after that time.

(Everyone talking at once - 1:14:11)

**Terry:** This is Terry. With house rules, there is an assumption of reasonableness in terms of respecting rights and everything. It's not like anything goes as long as everyone agrees to it.

**Lisa:** This is Lisa. A lot of places don't have house rules.

Male Speaker: Absolutely.

**Libby:**Moving on to R, visitors at any time.

**Tim:**This is time. I think this is a good question. I think that is the only one you need looking at the rest of this.

**Libby:**I have a question. This one was on several of the assessments. Tennessee 35, people sitting by the front door. What does that mean? Why would so many states ask that question?

**Melinda:** This is Melinda. I think that has to do with people who might be sitting in wheelchairs, like, at hospital, parked looking out the windows.

**Male Speaker:** Watching the world go by.

**Libby:**So that doesn't have to do with visitors really.

Male Speaker: Not really.

**Libby:**What does that have to do with? How does it relate? Several states asked that question.

**Fran:**This is Fran. My belief is that people are free to come in and take people out for walks if they want to or out to the store versus everybody has a certain place they have to sit, and you can't go beyond that. There is a visiting area and you can't go beyond that area.

**Victor:** This is Victor and I agree with Tim that the question is very good, but I also think the follow up exploratory questions are very good. It flushes it out. You can have the policy, but if it isn't, if you don't have the practice with it, there may be some cracks in it.

**Kyle:** This is Kyle. I would be fine with including that exploratory question too. It just...

**Male Speaker:** Which exploratory question?

**Victor:** 14 on page 24 with all the bullet beneath it.

**Libby:** This is Libby. Is it a house rule or a DDDS rule that you post visiting hours and create visiting hours?

**Lisa:** Neither. It's a home. You shouldn't have to.

**Terry:** This is Terry. I think the other thing I would recommend we cross out is the first bullet. It is covered by the fourth bullet.

Male Speaker: That's fine.

**Melinda:** This is Melinda. One of the things I wanted to say about some of the other ones when they ask like is there evidence of visitors. My concern is that is how we sometimes get into the sign in logs that we still have that are complete unhomelike. I mean, a parent has to sign in. I think that is more institutional. We look at, what is the proof of those things, I just don't want to end up as a provider putting things in place that look strange.

**Libby:**So the original question, this is Libby, does the setting allow individuals to have visitors at any time.

**Terry:** This is Terry. Wouldn't that usually be documented, Lisa and Melinda, in my D-notes, whatever they are called nowadays?

Female Speaker: Correct.

Male Speaker: When somebody visits...

(Everyone talking at once - 1:17:43)

**Lisa:**Like if someone's mother or sister came.

**Male Speaker:** So you wouldn't need a sign in type of thing.

**Lisa:** Well, we have to have sign in books now for the office of quality improvement, but they are changing the standards.

**Fran:**This is Fran. That will be up for discussion.

(Everyone talking at once - 1:18:06)

**Lisa:** This is a non-issue is how I look at it.

**Libby:**From a provider perspective, this is Libby, do you think the bullets under 14, any of those are relevant to ask?

**Lisa:** Well, it's someone's home. If they want to have visitors, they can have visitors. If their mother or sister wants to come, I mean, I had someone, God forbid, she was dying with hospice, and her parents came to spend the night all night. We are nice people. It's their house.

**Female Speaker:** I'm glad you are nice people, but there may be some providers not doing what you are doing.

(Everyone talking at once - 1:18:40)

**Terry:**I think there may be circumstances, this is Terry, where it starts to become an imposition. Someone's boyfriend/girlfriend happens to be there every night. At what point is that an intrusion?

**Laura:** This is Laura. I have had issues raised to me about privacy. Also, overly intrusive relatives who disrupt other people's lives. There are some nuances.

**Libby:** This is Libby. Just remember, privacy is under A. We are going to be getting to that next.

**Female Speaker:** They will come up again each other.

Libby:Right. Agreed.

**Male Speaker:** So, are we leaving in 14 now, the exploratory question?

**Jamie:** This is Jamie. I thought we said we were going to take out the first bullet?

**Male Speaker:** That I did hear.

Male Speaker: Right.

(Everyone talking in the background)

**Libby:** Are we leaving in bullet 1? Yes or no?

**Male Speaker:** That is the one we were taking out.

**Libby:** Are we leaving in bullet 2?

Female Speaker: Yeah.

**Male Speaker:** I think the key question too that we wanted was the one in R? Wasn't it? Then the bullets from 14.

**Male Speaker:** Do we want bullet 3 though? Are visiting hours posted? That goes back, that's almost kind of institutional.

**Tim:** That is part of the question. This is Tim.

(Everyone talking at once - 1:20:22)

Male Speaker: Okay. Thank you for the clarification.

**Libby:**Okay. So we are leaving bullets 2, 3, 4, and 5, under 14. We have R. Exploratory questions 4, bullets 2 - 5.

Moving on to S. Is the setting physically accessible to all individuals?

**Lisa:** It is if they live there.

**Male Speaker:** This gets very, very tricky. Only because what some may think is physically accessible, might not really be accessible. It's really tough to word these question. Such as, look at 18, grab bars, they may have a grab bar, but in some kind of ridiculous position for the person. We see it all the time. Not just in group, but in the general public. I love the question and we need it, but we need to be careful about how we set this up.

**Male Speaker:** I don't know the best way.

**Jamie:** This is Jamie. Aren't state homes obligated to follow OCEA and they have to have physical accessibility according to the guidelines of OCEA to become a home.

**Lisa:**I don't know. I have many homes that are not wheelchair accessible, unless they are a wheelchair accessible necessary house.

**Jamie:** That's my question.

**Lisa:**No. That is not a requirement.

Male Speaker: And the point being there is that it's the processing, but what can we do...

**Lisa:**Now, do I have grab bars in every one of showers and bath tubs at every house? Absolutely. But are all of my houses physically accessible? No.

**Female Speaker:** Some of the question is, there are two different kinds of #(Inaudible 1:22:45) 18 is talking about accessibility for somebody who needs accessibility because of a disability. Is it a physical environment, does it support the needs of people who require those supports? You are only looking at people who require those supports. The other question has to do with things that have been put up in the facility because, a gate or something like that, that is more for

behavior than physical accessibility. I have two different ideas. So, the question is, with #18, which is what Kyle is talking about more, when you bring somebody into a residence, have modifications been made to that place to make it accessible for that person.

**Victor:** This is Victor. (?) raises many good points. Just today I was having lunch with someone who uses a wheelchair and we were talking about a place here in Dover that is accessible in one way, it has a ramp to get into the restaurant, but the person said once you get in there, it's really not accessible to people who use wheelchairs because there just isn't adequate room around the tables. There can be a lot of gray areas with a question like this.

**Libby:**So, if we look at the exploratory questions, 18 first, are we okay to include those three bullets?

**Kyle:** This is Kyle. Yeah, I think they are okay. We may just need to take a closer look at these at some point. I know we are going to go over this, but of course the questions right now are okay. They kind of touch on some of the things. I mean, you might put such things later on when looking at it that are in compliance with the ADA accessibility guidelines or something like that. I don't know.

**Tim:**This is Tim. Another, while we are thinking about issue of physical accessibility, I know that DDDS has had concerns for years about our individuals falling. You can have the most physically accessible place, but it has a three inch lip on the front door.

Male Speaker: Then it's not physically accessible. It's not the most physically accessible.

**Tim:**Once you get in, maybe, but, I'm thinking of my son's apartment and that's exactly how it is. He trips over that sucker every other time. I think we need to think about that issue of falling. That can be debilitating for anyone. Especially for our people.

**Kyle:** This is Kyle. You could have, for this, a whole separate check list, and there are check lists out there to determine if something is accessible or not.

Male Speaker: Dozens or hundreds of items.

**Kyle:**It makes things more complicated, but it determines in a better way physical accessibility.

**Libby:** This is Libby. We are asking these questions about our current homes and this is for are they physically accessible for the individuals who reside in those homes, not all individuals.

**Lisa:** I only have five homes that are wheelchair accessible. Those are the only homes that I have folks that need that.

**Libby:** The current path seems to be that some homes are wheelchair accessible and some are not. That's just the way it is right now.

**Fran:** This is Fran. We do have some homes that identify themselves as being wheelchair accessible that the division would disagree with. They make accommodations that they feel are acceptable, for instance, hallways that are too small for a wheelchair to go down, the accommodation is that the person may be carried or put into a chair that isn't as wide with wheels to push down. The division wouldn't necessarily accept that as accessible, but the home, the facility does because they feel they can get people in and out if they need to.

**Kyle:** This is Kyle. That's my point exactly.

**Terry:** This is Terry. I assume for the question you have added Victors all of the individuals.

**Libby:** Well, for S, the overall question, I don't think we can say all of the individuals because not all of the current homes are accessible to all people.

**Male Speaker:** But to the individuals that live there. Maybe you want to change that to all individual residents. All individual residents.

**Kyle:**No. I don't think so. It's just the determining if the place is accessible to those individuals.

**Libby:**Who live there.

**Terry:** This is Terry. Unfortunately, and I agree that theoretically everything should be accessible, I have said that as often as anyone will listen to me, but in reality we have about 70% of our homes that aren't. So, the key question in my mind becomes is it accessible for those people who live there, considering their needs. And those needs will change too, which is a whole other challenge in our system, but I don't know if you want to look at accessibility in a home where people don't need it or them having to explain it.

**Lisa:**I don't think you can look at it Terry. They are not accessible houses. They are not going to look at it that way.

**Terry:**That's what I'm saying.

**Female Speaker:** That's what Fran said. I have had clients who lived in those houses that the providers say it's an ADA house and I look at it and say oh my God, this is not an ADA house.

**Terry:**ADA is not accessibility.

**Female Speaker:** #(Inaudible 1:28:45) My point is that they think they have done what they need to do and they haven't.

**Lisa:** Maybe there should be some bullets. Can wheelchairs go down the hallways? Are there roll-in showers? I mean maybe there need to be some of those specific bullets.

**Kyle:** This is Kyle. That is what I was talking about by the check list.

**Melinda:** This is Melinda. I don't want us to feel like the whole burden for making things accessible is on us. We are licensed by two entities, the state of Delaware, as well as long-term care. When they come in to license our houses, they have a huge environmental checklist and they take care of most of that stuff and they do know when things aren't accessible. Does it always get fixed? That is the question. But, for what we are doing here, there are two other tools for that, so, I do want everybody to feel that it's our burden alone on this question.

**Terry:** This is Terry. I like South Dakota's questions on page 26.

**Male Speaker:** I agree with Terry that a lot of these questions do cover important issues. I think a number of them are phrased where there are holes. Right. I do believe they go in the right direction.

**Libby:**Okay, so if we are going to try to move forward, for this item, which is physically accessible, I believe we said we are going to include all bullets under 18 for now, and maybe everything under South Dakota for now. What did we talk about for 17, exploratory question 17?

**Kathy:** This is Kathy. Could we move the third bullet under 17 to 18? I think that is one of the things that Tim was referring to earlier.

**Libby:**So, Carol, we are doing exploratory question 17, bullet 3, all bullets under 18, and...

**Kyle:**Sorry Libby. This is Kyle. So we are not using the first two bullets under 17? Is that what we are saying? Or we are just moving the third under 18 and keeping the other two. I'm just asking for clarification. I don't know what these things are about Delco strips and...

**Kathy:**This is Kathy again. When I read it, I looked at it, the question itself, the individual has unrestricted access, I didn't see this as accessibility as much as privacy. That is why I suggested moving the third bullet down to be accessibility and leaving the rest of it out.

Male Speaker: That's fine.

**Libby:**So we are keeping exploratory question 17, bullet 3, exploratory question 18, all bullets, and we are keeping South Dakota, all questions in for now?

Male Speaker: And just remove all redundancies.

Libby:Right.

Male Speaker: Keeping South Dakota, but we will revisit for...

## Libby:Right.

**Male Speaker:** Is there anything in the last one on Tennessee 42 about tables and chairs at comfortable height? If it's included somewhere else, that's fine, but if it's not, then that may be...

Female Speaker: Bullet 3.

Male Speaker: Thank you.

**Libby:**So, if you look at the thing that is highlighted on 27, need to assign...these are questions that were on different assessments that I didn't know where they belonged so I just kind of included them here.

**Terry:** This is Terry. I work with Suzanna, who chairs the day service group and I know they are spending a lot of time talking about person centered plans and I brought that up earlier that I thought was going to be a central focus in establishing and pursuing compliance with a lot of these things. I don't know if that merits discussion at this point in time, but I wanted to point that out that they are pursuing that pretty actively from what I have been told.

**Libby:**If we can set that on hold for now and move on to A, just to try to get through the other ones and I will make a note that we need to come back to those.

So, if we go to page 1. This has to do with quite a bit, right to privacy, dignity, freedom from coercion, and restraint. We have five pages of questions. Who wants to start?

I will start. I like exploratory question 12. I think those are all kind of good questions.

**Male Speaker:** I'm not sure what hair color has to do with coercion, but I'm sure it's an interesting story.

**Lisa:** Maybe a haircut #(Inaudible 1:35:05)

**Male Speaker:** Yeah. I can see some validity with that, but I'm not sure. It could be remotely tied in.

**Female Speaker:** I think they get the institutional bowl cut.

Male Speaker: Yeah.

**Tim:** This is Tim. I agree. I think 12 is definitely worth including.

**Female Speaker:** I'm surprised Victor isn't objecting to the question #(Inaudible 1:35:35).

**Male Speaker:** Sure. No. I'm focused so much on the question itself. It encompasses so much.

**Female Speaker:** Yes, but it is broken down into these separate exploratory questions. It addresses all these different things. It is huge.

**Male Speaker:** I think what you are talking about there is freedom to complete in terms of the real bullets. Freedom to coercion is much broader.

**Libby:**So, maybe if we decide which questions we like, maybe we can split this up into the privacy questions, I don't know. We can probably separate out the coercion and restraint questions from the other ones.

**Victor:** This is Victor. It also seems that it's going to be a lot easier to quantify and detail privacy and freedom from coercion and restraint than it will be dignity and respect.

**Libby:**And when we talk about privacy, we have already talked about locks on doors and knocking under a separate item.

**Terry:** This is Terry. I think we had agreed before that we are not going to repeat those things that are better covered under another item. Right?

**Libby:**Right. Let's just start with exploratory questions 11. I mean, let's just try to narrow these down a little bit and then we will review them again. So, the bullets under 11.

**Tim:**This is Tim. I like the telephone issue very much. Our son calls every night and that is very important for him. So, I think access to the telephone is very good. A question for providers, do all of our units have Wi-Fi?

**Lisa:**No. None of mine have Wi-Fi.

**Tim:**That is what I was thinking the answer was going to be.

**Female Speaker:** All of mine do.

**Lisa:** None of mine do. We are poor.

**Libby:** Do they have Internet?

**Lisa:** Yes, they have Internet. They have to have a computer for #(Inaudible 1:37:48) but we don't have Wi-Fi.

**Tim:** This is Tim again. Do the individuals have access to the Internet through your...

**Lisa:** If they want it. I have very few. Like I said, I have a very elderly population. I have a couple individuals that use the computer if they chose to. They can if they want. They use it to

look up recipes or shopping things or trips or stuff like that, but we don't have Wi-Fi.

**Libby:**So maybe that third bullet, this is Libby, instead of saying Wi-Fi and Ethernet, maybe it just, do they have access to the telephone and Internet.

**Male Speaker:** That would be better.

**Tim:**This is Tim. I agree.

**Libby:**Wi-Fi is a nice luxury. So, we are going to leave in those three, how about exploratory 12?

Male Speaker: Yeah. Everything. The haircut one seems...

Libby: The hair cut or the hair color? I thought...

(Everyone talking at once)

**Jamie:** This is Jamie, I'm sorry. To me, that is so excessively random. Like do they mean style? Like, you can't wear short...I don't get it.

**Female Speaker:** I think what they are getting at is everyone in the house having exactly the same haircut, because that's what they did. They had no choice in the hair cut.

**Jamie:**It's like do they have a choice in nail polish. I don't like...

**Male Speaker:** It's like asking if all the individuals have different color underwear.

**Female Speaker:** No. I don't think so. I don't think Delaware has ever had this happen, but I think other states have, where they gave everyone in the place the same freakin haircut.

**Male Speaker:** I hope that hasn't been recent.

(Everyone talking at once)

**Jamie:** This is Jamie again. I worked at Stokely Center years ago. And yes, all the residents got the same haircut, yes they did. I think what they mean here, and I think it's important that we don't make everybody wear the same color t-shirt, they have their own style, for lack of...I think it should be more than haircut.

**Libby:** This is Libby. If we keep going, there are many other questions here that dive into clothing and other things as well.

**Victor:** This is Victor. I'm sorry to go back to page 1, exploratory question 11, but did we say we

were leaving in the first bullet and taking out the third?

**Libby:**No. Leaving in all.

Victory:Leaving in all. I thought there was a tweak to the Wi-Fi.

**Libby:** To the third bullet, changing it to telephone jack and Internet access, instead of Wi-Fi and Ethernet.

**Victor:**But we are leaving in Internet access here. Thank you.

**Kyle:** This is Kyle. In about, this discussion about haircut, hair style, maybe we can word it, or there are other questions in there, there is a general thing about having personal autonomy to do things.

Libby: Okay. Page 2.

**Terry:** This is Terry. Can I make...#12, freedom to make complaints or grievances, or something like that. It's, coercion just doesn't seem to fit the exploratory question in my mind. I can live with it.

**Jamie:**#(Inaudible 1:41:17)

**Terry:** And I think that right to make a complaint and have it heard and responded to is important.

**Kyle:** This is Kyle. Can we just add that then? Make a complaint and then free from coercion. Individuals are free to make a complaint.

**Male Speaker:** That seems a bit odd.

**Kyle:**I mean, it can address, can the individual file an anonymous complaint, it's down in the third bullet too.

**Male Speaker:** What I'm saying Kyle is that most of the bullets, if we take out the haircuts, have to do with complaints. And you might want to have that question, it's a valid question. Do people have the opportunity to make complaints and have a fair hearing and so forth?

**Kyle:** This is Kyle. This is just a general comment, it goes back to the individual assessment too. I mean, a lot of these questions need to be asked to the individual too. About anonymous complaint, that needs to be asked to the individual also. That is just a broad comment on a lot of these questions.

**Lisa:**It does. And there is also, there is a policy, there is a client rates and policy where provides are expected to have the envelope posted with the anonymous forms if they want to do it. I understand like if we ask them, I understand what you are saying, but we do have things in place. Because we are going to have do decide, are we just going to do the provider assessment or are we doing three or four individual assessments in each house or the time line is going to get ridiculous. Do you know what I mean? And we haven't discussed that yet. The state is just asking for what Fran?

**Fran:** This is Fran. The state is asking that each facility does an assessment process, whether or not this group would like that to be one form or several. That is up to you to decide.

**Lisa:** They are giving three months for every provider to complete it, so we need to keep all that stuff in mind.

**Libby:** This is Libby. We need to complete this assessment before we move on to an individual assessment, so let's keep going, and high level here, if it looks okay, let's keep going and we'll word smith them in the next round. Exploratory question 16.

**Tim:** This is Tim. I find this one really difficult. Do any of the #(Inaudible 1:43:46) We have already dealt with that.

Male Speaker: You can cross that out.

**Tim:**Is informal communication conducted in a language, that is a totally different issue that they are trying to get at. Where some...

(Everyone talking at once 1:44:05)

**Tim:** Where some staff has English as a second language. And then the final one, is the assistance provided in private and appropriate when needed. I don't know about that one.

Male Speaker: That's a privacy issue.

**Male Speaker:** That was already covered.

**Lisa:** You don't have to use every one of these.

**Male Speaker:** The second bullet though is something that I would think is pertinent. That might be the only question there that's pertinent. And drop everything else.

**Male Speaker:** I would be comfortable with that.

**Libby:**So we will keep the second bullet on 16. 20.

Male Speaker: I like the first bullet.

**Female Speaker:** #(Inaudible 1:44:42)

**Female Speaker:** I like the second one. The first two and the second two are conceptually

different.

**Jamie:** I think kind of the same way. Kept private instead of in public view Keep the language.

**Libby:** I wrote the same thing.

**Kyle:** This is Kyle. I think the third bullet in 16 could go under...

**Libby:** They are not being grouped like this in ours. They will just be questions. So we will keep all four on 20?

**Kyle:**But I'm saying that third bullet on 16 could be under 20, under privacy.

Libby: Yeah. Right. The third bullet yeah.

**Female Speaker:** So take out the third bullet?

**Libby:**Exploratory question 21.

Female Speaker: I thought the second bullet was most appropriate.

Libby: I agree.

**Tim:** This is Tim. Sorry I didn't hear.

**Male Speaker:** The second bullet was most appropriate.

**Terry:** This is Terry. I have known clients where if you are honoring individual choices they are not necessarily going to be appropriate to the time of day and weather and so forth, but that is just an observation.

(Everyone talking at once)

**Victor:** This is Victor. I'm sorry to go back to 16, the exploratory question, the second bullet, which we all agreed is tremendously important, but now, the way it's phrased, is formal, oral, and written communication conducted in a way the individual understands. This is such a loaded issue. Individuals who need assisted technology to understand something for example. This says what it says, but it doesn't address so much more, as far as receptive communication issues and others as far as what people need in order to understand or have their needs understood by others.

I raise this because as with some others that we tabled for later, we could detail this an awful lot or not so much, depending on how we all feel.

**Male Speaker:** We could include it and tweak it later.

**Libby:** And it will make a note that that might be an individual assessment question as well.

**Kyle:** This is Kyle. I think we will word smith it at a later date, but I mean, to cover all bases, you could say, are different communication needs accommodated and that would take in effect...

**Male Speaker:** That doesn't take into consideration Tim's concern about people speaking other languages. I know in our homes...

**Male Speaker:** It's about an accommodation to meet their communication needs. Spoken language.

**Female Speaker:** Are you talking about staff?

Male Speaker: Yeah.

Male Speaker: We could work on the language later.

**Fran:** This is Fran. I think overall staff speak English, the question is, is it understandable to the individual because of accents, English isn't spoken well...a command of the language.

**Male Speaker:** What is understandable?

**Terry:** This is Terry. I think, I had staff that would speak Swahili and we finally said, you are in the consumer's home and you should speak a language they understand. That is just one of the issues we confronted.

**Libby:**Okay. So how does that change any of these questions?

Male Speaker: It doesn't. It's just nuances of the issue.

**Female Speaker:** That is not what they are asking. I mean, yeah.

Male Speaker: But it is an issue.

**Female Speaker:** What if somebody needs sign language or somebody...

Male Speaker: Needs a communication device.

**Female Speaker:** Or has, it gets tricky, has their own, I don't know how to describe it, I have

had clients who sort of had their own language.

**Libby:** This is Libby. So Laura, what is your recommendation?

Laura: I think we should put it in. But ask more questions about it.

**Libby:**Specifically what Laura?

**Kyle:** This is Kyle. We could word smith it a later time.

Male Speaker: I agree.

**Libby:**Okay. So we are not losing it if we don't make a note.

**Kyle:**I think it's going to take a little bit of effort because if we have that many questions about it...to put it down.

Female Speaker: And the bullet seems like it would fit well with #22.

Female Speaker: Yeah.

Male Speaker: Hmm.

Female Speaker: Yeah. It's about communication.

**Male Speaker:** That about as dignified as...

**Libby:**So 22, leave in all bullets?

**Victor:** This is Victor. Certainly the last bullet in 22 would also need to be asked of the individuals.

Male Speaker: I think they are all conceptually sound.

**Libby:**We must be close to 3:30 because nobody is responding.

**Female Speaker:** We like them all. Right?

Libby: Okay. Thank you. 22 all bullets.

Male Speaker: That's Sweetie.

Female Speaker: Thanks Hun.

(Everyone talking at once - 1:50:48)

**Male Speaker:** It is almost 3:30, you can tell.

**Kyle:** This is Kyle. You notice Tim in that last comment didn't say his name.

**Libby:**Okay. If we finish page 2, and then we will save the rest for later. Exploratory question 3.

**Male Speaker:** That is already addressed everywhere else.

**Tim:** This is Tim. Have we talked about camera present issue? Now that is an important issue.

Libby:No.

**Male Speaker:** Move that into the privacy section. That is my suggestion.

Female Speaker: I agree.

Male Speaker: Soon you will have cameras on wrist watches guys. Just remember that.

**Libby:**So, exploratory question 3, first bullet, then we will stop there. I think we have another full meeting to get through here, to get through the rest of this. How about if we can all make your notes, so when we ask about these bullets, you can say yes or no, or this is the change I want to make. We might be able to get through these a little quicker. If we all do that...

**Kyle:** This is Kyle. Which ones do we need to review for the next meeting?

**Libby:**We need to finish A, go through B, we need to go through C, then we have J, K, and L. If the agenda starts with those items next time, then if we have time, we can start the discussion on the responses. Is there anything else we should include in the agenda for next week? Our next meeting is next Thursday.

Male Speaker: I think Denise wanted to make a comment.

**Denise:** I was told last time that I was breaking the rules to let me talk.

**Libby:**No. I didn't say that. You are not breaking the rules. Denise, we agreed at the first meeting that anyone can speak up as long as it's relevant.

**Jamie:**#(Inaudible 1:53:07)

**Kyle:** This is Kyle. Yes you can speak up. Maybe the other group didn't, I don't know.

**Libby:**Did you have something you wanted to add?

**Denise:** Yes. Because I'm on the other committee, the one for day services #(Inaudible 1:53:25)

**Libby:**Could you speak up or move up a bit?

**Female Speaker:** Terry, do you mind moving that down?

**Denise:** This is Denise and I'm on the day services committee also and they had a few things they wanted to send over here. We had a question on our forms about voting rights and is that facilitated. And they didn't think that was in their area to facilitate or do anything about that, that it belonged in residential. I disagree. I think it should be across the board.

**Libby:** They brought that up at the beginning of the meeting and made note of it so I will put that on the list for next week to make sure we cover voting.

**Denise:**We did talk about assisted technology also in the work place or the day services place, as well as everywhere else that people might need, like when they go to school and they have a talk board, and that stays at the school. That doesn't go with them, and sometimes that's a problem. And when we were talking about language, we were also talking in a manner that the person can understand. I was talking to Tim about Bill, when I speak to Bill, that sometimes you have to put things in different sentences or phrased in a different way to ensure that a person might understand what you are asking them, or what they are asking of you. And things like that. I'm just saying that we brought that up there and maybe it's appropriate here also.

**Kyle:** This is Kyle. I agree. I think that part of that question...

**Victor:** This is Victor. #(Inaudible 1:55:06)

**Denise:** And one other thing, last comment, is the CMS rules, we brought this up too. They were talking about deviation and they were talking about actual percentages of compliance, and all of that in that group, which I totally disagree. The CMS rules, you are either in compliance or you are not. And the only deviations are according to the person centered plan, if it's documented in the person centered plan that the person can or can't do this, and the reasons for it, and what has been tried ahead of time, instead of the final say so, like, no you can't have food other than what is allotted to you because you have Prater-Willy Syndrome.

**Libby:**I'm sorry. This is Libby. What is your point on this?

**Denise:** That the CMS rules are saying you have to, it's the facility that needs to be in compliance and they need to be able to answer yes to most of the basic questions that CMS requires and deviations are allowed, but only on an individual basis that each person needs and that has to be documented in their person centered plan.

**Libby:** And I think that goes back to what we discussed previously, that goes into the answer

responses and what will be appropriate documentation and yes is yes, but yes with additional information might also be acceptable, but we need to discuss that and we will start that discussion next week.

**Kimberly:** This is Kimberly. There is also in the CMS rules the ability for heighted #(Inaudible 1:56:53) You can have approval that you are meeting the CMS rules. This is not necessarily a black and white scenario.

**Female Speaker:** That is only for the actual physical setting. There is a very narrow area where that is an available procedure, like if you are on the grounds of the facility or the institution, for example. That is a very narrow area. It is not open across the board.

Libby:Okay. Thank you very much. Time is up. I will see you next week.